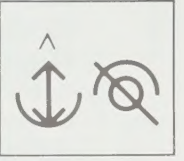
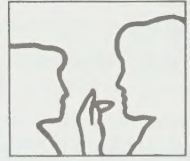


COMMUNICATING TOGETHER



A QUARTERLY MAGAZINE ABOUT AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

VOLUME 8, NUMBER 2

JUNE 1990



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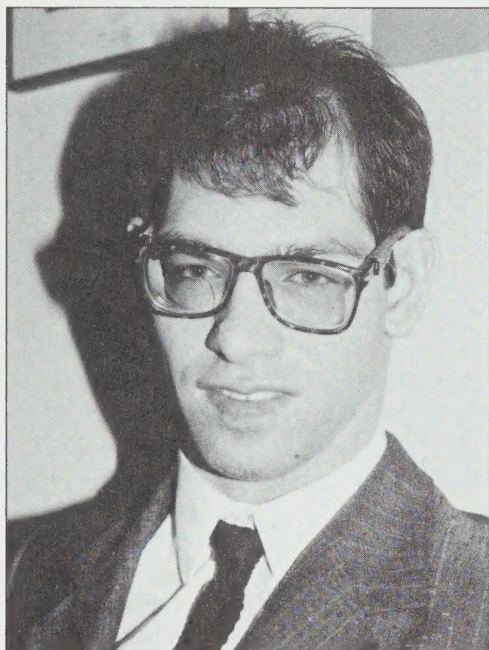
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MY FIRST ENCOUNTER WITH DEATH

JOHN DOWLING



John Dowling is a computer clerk for the computer conferencing network CONFER, administered by the Easter Seal Communication Institute (ESCI). He first became involved with augmentative communication in the early nineteen seventies when he began using Blissymbols as his communication system. At that time he was in the original communication class at the Ontario Crippled Children's Centre (now the Hugh MacMillan Rehabilitation Centre). John uses his voice for most of his communication now, sometimes augmenting it with spelling and gestures to make his point. He is an experienced public speaker, being a member of the Community Awareness Project team of presentors sponsored by ESCI. John wrote the following article following the untimely death of his step-sister.

I had my first close encounter with a death in the family several months ago in the latter part of December, 1989. Prior to this, death was a distant experience; one that touched others but not me. I am a person with cerebral palsy, and I use a wheelchair and have very poor verbal communication skills. It was at this time that I realized how difficult it was for me to deal with the emotional aspect of death.

First, I was unable to express how much pain I felt for my family

because from a wheelchair I could not reach and embrace those who were hurting. They could hold one another easily. Sometimes, I needed to hold them and to be held. Since this was not easy for the family or me, I feel I have not let them know how much I love them, and miss the person who died. I also need to be held close physically to mourn the loss of a family member or a friend who is close to me. Since the funeral, I have returned to my home where I live alone. From a distance, I think of them all the time, but cannot be close to talk and to embrace them. This makes mourning a very difficult and long experience.

It is difficult at a time like this for anyone to know what to say. It is also a time of strong emotions which make communication difficult. Added to this is the fact that I am almost non-verbal and feel even more non-verbal at times like this. I knew I should say words but the ideas were all mixed up because of my emotions. All I could do was cry. That was not enough, I know, but it was all that I could express at the time. I needed to express my sadness to the family and let them know that I, too, was participating in the family's loss.

Saying Good-bye

Going to the funeral home to say good-bye was very difficult for me since I am never sure whether I will cry or laugh when I am extremely emotional. When I laugh or cry I cannot do so quietly. I know it is inappropriate but I cannot control it because of my cerebral palsy. My family insisted I go to the funeral home when there were not too many people there. I have mixed feelings about having gone, but felt it was important for me and for my family to do so. I felt I could not handle the funeral service so I stayed home and cried by myself.

From this experience I have learned the following:

1) It is more difficult for some persons with cerebral palsy to participate in the loss of a loved one than someone without this condition, but

it is just as important for them to have the opportunity to be held and to hold and to express their feelings in whatever way they can.

2) It is important that the person who is physically disabled is told about the loss and permitted to participate in whatever way he or she can during this difficult time. It makes mourning easier when you are allowed to be part of it.

3) It is important that the physically disabled person has someone he/she is close to to talk about it or even cry and hold each other. Since I had persons who really cared, I was able to call them or talk to them personally. It made it easier for me to cope with the tragedy, because they permitted me to express how I was feeling emotionally and physically.

4) I have also learned in talking to other people with cerebral palsy that they were not wanted by their family at the time of the funeral or after. This made it an even more difficult experience for people in this position to deal with the bereavement.

5) It is important for physically disabled people to deal with their own death and to be permitted to talk about it whenever they feel they are ready to understand what is involved.

I hope that these thoughts will help others like me to deal with death and will also help members of the family or our friends to understand what we are needing and feeling at difficult times like this.

In writing these thoughts with the help of a friend, I re-experienced much of my original emotion and also felt some release through the process.

If you would like to share your personal experience or additional thoughts or ideas, write to me c/o *Communicating Together*. □

New from BCI !

Blissymbolics Communication International

is proud to announce the release of

AccessBliss 1.0

AccessBliss (© 1989 BCI) is a program for the Macintosh™ computer that enables the user to find and retrieve quickly and easily any currently approved Blissymbol. The Blissymbols are copied to the clipboard for subsequent use in wordprocessors such as MacWrite™, Microsoft Word™, or WordPerfect™; painting or drawing programs such as MacPaint™, MacDraw™, Ready Set Go™, SuperPaint™, or HyperCard™; in fact, virtually any Macintosh application program.

AccessBliss is easy to learn and easy to use. You will be copying and pasting symbols within minutes of starting AccessBliss, even if you have never used a computer before.

AccessBliss allows you to:

- find any Blissymbol in less than 5 seconds
- use your choice of 4 different symbol finding methods
- copy multiple symbols to your clipboard
- add the indicator(s) to a symbol with a single click of the mouse
- save the standard reference grid along with the symbol if you choose
- save the word along with its symbol if you choose
- format the clipboard in rows or columns
- access any symbol synonym directly
- save the Blissymbols in text or picture form

Example of Blissymbols from AccessBliss

∕ ^ \ ^ +! ⊕ ⊕
"This is a good tool to use."

Minimum Technical Requirements:

- Macintosh Plus, Macintosh SE or Macintosh II with 1 Megabyte or more of RAM
- AccessBliss is a HyperCard stack and requires HyperCard 1.2 or later version
- Hard disk with 10 Megabytes or more of memory is recommended but not necessary

AccessBliss package includes:

- AccessBliss program, developed by Russell Galvin, Geliefan Enterprises and Fraser Shein
- AccessBliss Users Guide, a complete step by step instruction manual for using AccessBliss
- BlissTemplate Font © 1989 BCI, developed by Peter Reich, University of Toronto
- BlissTemplate Font installation guide and instruction manual

AccessBliss is available for \$250.00 from:

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Advertisement

Skallagrigg

KARI HARRINGTON



Kari Harrington was in the original Blissymbol class of 1971 at the Ontario Crippled Children's Centre. Since then, she has completed elementary school at James Robinson Public School in Markham, Ontario, and more recently, high school at Langstaff Secondary in Richmond Hill. She is attending a life skills class at Markham Participation House, and hopes to move there soon.

Last Christmas, a very special friend gave me a very special present — a book called "Skallagrigg". I looked at the strange title. Then I looked at the last page. It was numbered 728. Never in all my life have I even tried to read anything that long. If I had been shopping in a book store, I would not have got any further than that. I would have moved on to find something much shorter, with a title I could at least say in my head. If I had done that though, I would have missed out on one of the most wonderful, thought-provoking novels I could ever hope to read or hear.

My friend must have known I might be put off by the length of the book so she wrote a little note inside the front cover. That note made me interested. Then, when I read that the author, William Horwood, had a daughter with cerebral palsy, that made me more interested. By the time I read the back cover, I was hooked. It said the story was about Arthur who had been abandoned as a little boy in a hor-

rible hospital in England. Esther was a very bright, young girl severely involved with cerebral palsy. The story would be about why and how they finally met. Another important person was Daniel who was an American computer-game genius. All in all, my kind of story!

The book is divided into five parts. It was slow-going through Part I, but I kept at it because I knew it was going to get better and it sure did. I was soon so wrapped up in all the different things that were happening, the pages just skimmed by. (By the time I got near the end of the book, I new how important Part I was, so if you try reading it, don't decide to speed things up by skipping it!) Skallagrigg is a story about long ago and also a story about now and the future. It is happy and sad, exciting and scary, and, in a way, it is filled with hope.

Now a word about that strange title, Skallagrigg: Who or what is Skallagrigg? Where did the name come from? The book was written in English, but is the word from another language? At one point I thought it was the name of a special God for differently abled people. You may think something else. Trying to find out is another thing that makes this book so interesting and keeps you reading and reading for seven hundred and twenty-eight pages! □

Reference:

Skallagrigg, by William Horwood, 1987. Penguin Books Ltd, 2801 John Street, Markham, Ontario L3R 1B4

Editor's Note:

Kari always like to get mail from readers around the world. If you have news to share in "Family and Community" write to:
Miss Kari Harrington
16 Jonquil Crescent,
Markham, Ontario, Canada
L3P 1T4

Hamilton-Wentworth Essay Contest

The Hamilton-Wentworth Communication Collective recently conducted an essay writing contest, first prize for which is an expense paid trip to the ISAAC conference in Sweden, August 12-16, 1990 for the winner and an attendant. The competition was open to augmentative communication users sixteen years of age and over who are residents of the Hamilton-Wentworth or Burlington areas of Ontario. Essays were to be no more than 500 words in length. Several excellent essays were submitted: the winning one was by Paul Marshall whom many readers will recall wrote the feature article in the last issue of Communicating Together. Over the next few issues, we will present a selection of the submissions. Following is Paul's winning article, and one by Robin Wood. Congratulations go to all participants, and we hope Paul and his attendant have a wonderful trip to Sweden.

Augmentative Communication: The Call of One's Life

PAUL MARSHALL

I can remember those silent years when my mind was overflowing with questions that were not being answered: remembering the *want* to verbalize my thoughts, dreams, and hopes, and desiring to share and grow in my world. Life began turning into a room with many windows and a door without a key. With no English skills, my locked room symbolized the turmoil and the war within me where I became more depressed, and was the converse of my "window world" that looked so delightful and full of life. If only I could find a key named communication, then the door would be unlocked. During those days my world seemed all negative, but was it? The key to the outside world came at age twelve, ending the silent years forever. My inner world opened up, thanks to an augmentative communication system named Blissymbolics. All the countless questions, thoughts,

dreams, hopes and wants came flowing out. For the first time, I could communicate with the world.

Learning really started with Bliss. Reading came very slowly. With its development came a greater thirst for education and an attainment of living skills.

Mastering communication skills on a Blissboard, however, was not the end of communication problems. Sometimes people would steer away, because they were afraid of the unknown. Trying to get my education was a battle. It is difficult to fit into a world that requires its population to verbalize rapidly. This is the struggle of being nonspeaking. The daily trials do chip away at the human spirit if you allow them to. Yet I seek to live as normal a life as I can, to be a useful and contributing member of society. By the great fortune of learning Bliss, I have been able to achieve computer and several college courses. A person can overcome with perseverance, the right tools, and the support of teachers, family and friends.

As a nonverbal person, I have an important task to live out. Every time I do something with my own life, I am putting on another light for the nonverbal population, saying "Hey, we all need each other."

Augmentative communication has enabled me to contribute. For example, I am involved in my community: church, church newspaper editor, and writer, counselling street kids (see *Communicating Together* Volume 8, Number 1), and the family farm. I am blessed to have ways to communicate, whether it is Bliss, a computer with a voice synthesizer, or the power of the printed word. Trials are not necessarily negative: it is what you do with them that make them negative or positive.

Augmentative communication permits me to live a life full of quality as a *human being*, not a "nonspeaking", "handicapped" or "normal" person, but as a person who communicates in society, both in word and deed.□

**This section of
Communicating Together
is sponsored by
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Ontario District.**

All This and I Still Need to Talk

ROBIN WOOD



Undeniably I have problems communicating. When I was very young, I talked with my eyes and with gestures. Then, with a lot of patience and understanding from therapists and teachers, I learned Blissymbolics. At first Bliss gave me the ability to say what I wanted, but symbols did not always help in initiating a conversation with verbal persons. There was an alphabet line, but I didn't know how to spell. I started reading the words under the symbols and memorizing the spelling.

Next came a combination of this huge Blissymbol board and an Apple computer. This system of communicating was so complicated it tires me to even give the simplest explanation of how it worked. Anyway, I like to look at someone when I talk with them, so I know they are following my conversation. With all this extra equipment, extra set-up time, and extra frustration, I'd lose the person's attention before I'd begun to speak.

Then came the Touch Talker. It was going to be my voice. Conversation was going to happen any time I wanted as long as someone turned on the switch. Have you ever known a disappointment? I have: with the different accessing switches for my Voice Output Communication Aid (VOCA)! There was a switch mounted to the left side of the head rest on my wheelchair that I pushed with the side of my head — it moved around all the time. Then there was a switch that I operated with my knee. It stuck out and was dangerous. There were about three different styles of hand switch — I experienced pain in my

arm from pushing them. I used a head pointer and looked like a weirdo, and was always stabbing myself. Next I tried using just my fist. This was good, except my hand was always raw. The last resort was a hand splint to protect the area that touched the machine. At the same time, while all this hard work was going into the Touch Talker, I finally convinced everyone that I could handle a regular word board. I had thought about this long before anyone else. It's a good thing I'm persistent.

For now the VOCA is on the shelf. I'm confident that we will find the switch best suited to me sooner or later. I still have my Apple computer and it's great when I have a couple of hours to spend on it to write my thoughts down. The best means of communicating right now is my word board.

I have BIG plans for my future, and they revolve around independence through communication. At the end of this year I will be living with two other young adults. After high school I plan to attend Mohawk College to study Early Childhood Education. Then my dream is to teach children with special needs. Wouldn't it be great for me to converse with my students spontaneously?

My challenge to anyone is to devise a faster way to make my dream a reality!□

Join ISAAC Now

The International Society for Augmentative and Alternative Communication (ISAAC) offers four types of memberships:

- Student Membership
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Members of ISAAC are entitled to reduced rates for: *Communicating Together*, *Communication Outlook*, *Augmentative and Alternative Communication* (AAC journal)

For membership application and other information about ISAAC write ISAAC, P.O. Box 1762, Station R, Toronto, Ontario, Canada, M4G 4A3.

Collaborative Consultation: A Model of Service Delivery (Part 1)

NAOMI GIBSON

Naomi Gibson is director of the Educational Service Program of the Easter Seal Communication Institute (ESCI). Prior to joining ESCI, she spent several years teaching in the field of special education. Most recently she was with the Computers in Education department of the Ontario Ministry of Education. She organized the recent ESCI symposium on Collaborative Consultation.

Toward the end of the winter, in early February, a group of people congregated at Cedar Glenn, near Bolton, Ontario (northwest of Toronto) for a symposium on collaborative consultation. Those participating represented professionals from education facilities, and from the augmentative and alternative communication (AAC) services within children's treatment centres across the province.

The goals of the symposium were:

- to clarify and better understand the concept of collaborative consultation and its relevance to the education of students who are AAC users;

- to identify potential roadblocks and strategies for achieving collaborative consultation in Ontario.

The symposium featured two major presentations, both of which prompted considerable, thoughtful discussion. The first was by Anne Jordan-Wilson, chair of the Special Education Department of the Ontario Institute for Studies in Education. The second was by Stephen Calculator, professor in the Department of Communication Disorders at the University of New Hampshire. In this, Part 1 of the report on the symposium, the major elements of Anne's presentation are outlined, along with the list of indicators of collaborative consultation drawn up by the participants.

Anne delineated three major models that prevail in the delivery of educational services to children

identified as exceptional: the "restorative model", the "minority rights model", and the "environmental model". She postulated that each could be viewed as a state of mind, a reflection of the attitudes of those working with the children. In a very general way, let me describe the three models as they were presented to us.

The "Restorative" Model

The first, the "restorative model", refers to the situation in which there is confirmation of deficit; all other characteristics of the student fade, and the focus of the consultative support is the student's deficit. The restorative viewpoint is the most common, and should not be considered to reflect a lesser concern for the students or their needs. However, the model of service delivery that accompanies this viewpoint is based on the attitude that the student has a problem, that someone is a specialist in dealing with the identified problem, and should therefore have responsibility for looking after the student's program that addresses the area of deficit.

Understandably, this model is based on students having an absolute, identifiable characteristic or deficit, and tends to result in segregation, and a fragmented service delivery process.

The "Minority Rights" Model

In a "minority rights model", again the student is labelled according to an identified exceptionality. However, unlike the situation in the restorative model in which the professionals determine the nature of the support the student is to receive, the student, by dint of his or her membership in an identified group, is assumed to have rights and/or control. This model is becoming pervasive, supported by legislation such as Bill 82¹, and Section 15 of the Canadian Constitution², which guarantee minority groups equality under the law. It implies the proviso for compensation and additional resources compared to



Anne Jordan-Wilson

the majority, in an attempt to correct imbalances that have prevailed.

Like the restorative model, the minority rights model depends on the identification of deficit, and on service delivery that focuses on that deficit. And like the restorative model, students are either in or out of the identified group; they qualify or they do not qualify on absolute criteria for rights assigned to the group based on whether or not they are identified as having specific traits or conditions.

Both the restorative and the minority rights models raise questions about the means of identification which must result in absolute definition of categories. Who "gets in" and who does not? By what means are the categories defined, and against what measure? And does identification of a student as a member of a group become necessary in order to obtain service or support for him or her?

The "Environmental" Model

The final model, the "environmental model" involves looking at the student in the context of the educational community and identifying ways in which it is failing to meet his or her needs. Thus the problem is seen not so much as an absolute deficit that the student possesses, but as a problem relative to the educational setting that results from

the interaction of the student with his or her educators.

Students are seen as individuals having difficulties that rest, at least in part, within a given learning environment and within the context in which they are learning. The model acknowledges the whole student, recognizing that, like everyone else, he or she has a profile of both strengths and weaknesses.

The environmental model is seen as the one most suited to collaborative consultation since it involves enabling teachers to view themselves as capable of addressing the difficulties the student is encountering, with the assistance of consultant(s) also working with the student. There is an attitude of shared responsibility that prevails, with each of the professionals involved having equal status in the decision-making and program planning process that takes place.

For teachers it involves assuming responsibility for finding more effective ways of working with the student, rather than looking to others who are more specialized in dealing with the deficit to take him or her out of the class for special instruction. For consultants it involves enabling teachers by increasing their skills, and helping them to develop the strategies they need to work more satisfactorily with the student and with subsequent students exhibiting similar needs.

While this represents a move toward indirect service for the consultant who may have been schooled in a direct service model, the payoff lies in the knowledge that the student's needs are more likely to be better met within the day-to-day program rather than just when the specialist is present.

Anne identified two major overlapping limitations: the time involved in shifting attitudes (among educators and consultants); and the reality that some consultants may not want to relinquish their direct service involvement, while some teachers may prefer to continue the consultants' method of direct service.

She put forward three goals for consultants working in an indirect service delivery mode:

- 1) Solve the immediate problem
- 2) Increase the client's (teacher's) skill so that he or she may work more effectively in the current situation, and handle subsequent

- situations more satisfactorily
- 3) Negotiate a change in attitude that involves moving toward shared responsibility for students, their learning, and their progress.

Following a discussion about the evidence of each of the three models in the participants' workplaces and in attitudes of colleagues and clients of those with whom they work, the group developed the following list of characteristics of collaborative consultation.

Collaborative Consultation Checklist

- The participants have a plan to share expertise interactively.
- There is an agreed upon goal.
- The plan is *mutually* agreed upon by all participants.
- Each participant's contribution varies depending on the nature of the situation.
- There is situational responsibility, depending on the nature of the problem, and the participants' knowledge.
- There is a demonstration of generic consulting skills.
- Difference and beliefs around the consulting process are identified.
- All stakeholders are involved in the process.

- Each participant's contributions are equally valued.
- The consulting process involves continuous feedback and change.

In the next edition of *Communicating Together* we will outline Stephen Calculator's presentation in which he focused on a rationale for collaborative consultation, and ways of measuring its success. As well, we will include the list of barriers to collaborative consultation identified by the participants. □

Editor's Note

1. Bill 82 refers to an amendment to the Education Act of Ontario, which brought in equal access to education for all students in Ontario. It identified the following "primary handicapping conditions": learning disabilities; communication exceptionality; intellectual exceptionalities; physical disabilities; behaviour disorders; and multiple handicap.

2. Section 15 of the Canadian Constitution is known as the equality clause. It makes proviso for equal protections of all people regardless of, among other things, disability under the law.

Your reaction to any of the information in this article is invited.

From the leading edge of the nonspeech communication movement

AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

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Editor: **Lyle L. Lloyd, PhD**, Professor of Special Education, Professor of Audiology and Speech Sciences, Purdue University

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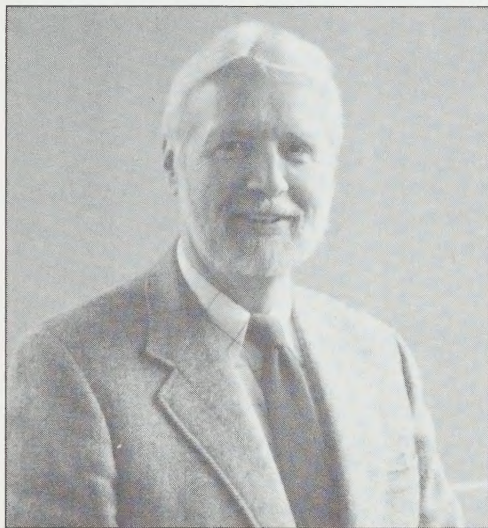
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A Talk with David Yoder: from Literacy to ISAAC, with Lots in Between

SHIRLEY MCNAUGHTON

Shirley McNaughton is the former executive director of the Easter Seal Communication Institute (ESCI). Although officially "retired", she continues to participate actively in the field of augmentative communication, lecturing, writing and following her first love — finding new ways to apply Blissymbols to today's technology.



David Yoder

David Yoder has been called the father of Augmentative and Alternative Communication (AAC) — and it is a well-earned title. He has been nurturing AAC since its earliest days, speaking in support of the fledgling field across North America in the seventies and eighties, providing a role model both to AAC clinicians and to masters and doctoral students who studied with him at the University of Wisconsin-Madison, serving as first editor of the journal, AAC, and currently, along with his responsibilities as Chair, Medical Allied Health Professions, University of North Carolina at Chapel Hill, giving leadership as the first president of the United States Society for Augmentative and Alternative Communication (USSAAC).

David Yoder is a colleague I've long respected and enjoyed working with. When the opportunity to interview him for *Communicating Together* arose, I was delighted. He was in Toronto in November, 1989, along with David Koppenhaver, giving a workshop entitled "Teaching Children with Physical and Speech Impairments to Read and Write". At the end of the workshop day, we talked! The topics we explored took us from the theme of the workshop, literacy, through many shared concerns, to the ongoing need to broaden our thinking. Here are David Yoder's perspectives.

Shirley McNaughton

Literacy

I have been interested in the literacy issue for some time. Through the years, I had seen a large number of individuals coming to our clinic in Wisconsin who were unable to take advantage of the technology that was available to them because they were illiterate. This gets us into a double bind — we need the technology to assist us with teaching literacy skills and at the same time, if they're not literate then that impinges upon the efficiency with which they can ultimately use the technology. It wasn't until three years ago, when David Koppenhaver, a graduate student at the University of North Carolina at Chapel Hill studying the relationship of language behaviour and reading, responded to my invitation to focus upon literacy problems with persons with severe speech and physical disabilities, that there was an opportunity to relate to my concerns.

One of the valuable things that I have learned in investigating some of the literature in literacy is the term of "emerging" literacy. It gives us the notion that it evolves. For years we've talked about emerging language. It's an evolutionary process, and the more I look at what we are thinking about in terms of emerging literacy, they are the very same things that we talk about with regard to the emergence of language. But we

must get our priorities straight. We really have to have an interpersonal communication system in place before we begin the more advanced emerging literacy activities. The language and communication system can be a very simple one, but we've got to have one that's functional and useful.

Parents

We've got to spend more and more time with the families of AAC users. Supporting the emerging end of the language and literacy continuum is the natural role for families. As clinicians, we have to come, from the very beginning, with the attitude that there are parents who have fostered good rich communication, "Yes, your children have learned, they're learning a good rich communication — look at the way they're interacting with you — their eyes, their gaze, their facial expression, their body language." This goes on in a very rich way with all children regardless of what the physical problem may have been before the emergence of words.

The early things that parents do in interacting with their children, the way they read with them by looking at books and doing a lot of reading together: this along with observing a writing mom and dad, a reading mom and dad, reading brothers and sisters, provides a model. When young AAC users see this type of behaviour taking place at home, it adds to their expectations of themselves that of course they will do the same thing.

I think part of our role as professionals is to encourage interaction between parents and their children who are AAC users, and to help parents develop the attitude that they can do it. The parent needs to be better equipped to orchestrate the whole picture. That puts a lot of onus on parents; however, the assertive parents who are really looking out for the whole picture get the best services for their children.

Teachers

Somebody has to be responsible for the holistic approach and the holistic view, and I see that person as the teacher. In this day of specialization, I think we may have begun to abdicate some of the overall responsibility of children's acquisition of knowledge to the specialties. There needs to be a way to empower teachers to assume, in a collective way with the specialists, the responsibilities for teaching — regardless of whether we are basically concerned with language, communication, literacy or whatever it might be.

The last three summers I have been teaching a seminar on language skills of severely handicapped people. There have been special education teachers, speech language pathologists, occupational therapists, physiotherapists, psychologists — they're quite an interdisciplinary group. One of the questions that I have asked the group every summer is, "What are your notions about teaching reading to individuals who do not use speech as their primary means of communication?" I was shocked the first time this question happened to come up in a discussion, that over half of the teachers were saying, "Oh, no, they can't learn to read; they're not talking." So I began to pursue this and I am continually being shocked that even with people who are being prepared to be teachers of special populations, somehow the myth persists — if you cannot talk you will not read. It is something we have got to get out of the heads of our teachers. If they are assigned the responsibility of teaching our children and they themselves have the notion that the children are not going to read, then they're not going to do those kinds of things that will assist learning literacy.

By the same token, I think we have to build in from the very beginning the notion that communication is what we're going to focus on, and from that evolves language. We have to emphasize that communication and language are not synonymous with speech and that although the motor act of speech is something that our severely handicapped children don't do, this does not mean that they don't have and can't acquire language, or that they can't master a good rich communi-

cation system.

One thing that we can do is develop video tapes with our literate AAC users, as examples for teachers. We can begin to demonstrate — yes, here is a group of individuals who can learn to read and can learn to write. We need to start very early and assist in the emergence process.

Successful AAC users as role models

David Koppenhaver and I went to the literate adult AAC users to find out why or how they may have become literate. I think we would have similar findings if we went to the good AAC users to investigate what it is about them that has made them competent communicators. I would venture a guess that we would find that some of the same things that have made them good users have made AAC adults literate: they're more assertive; they have a lot of real self confidence; they come from a family that had expectations that they would learn to read and learn to communicate effectively and one that is very interactive with them; they have had lots of experiences outside of the home and in the community; they have travelled; they have become more worldly. A great deal comes back to the confidence that they have in themselves and what the family's expectations and interactions were.

Interaction

Along with the attention I'm currently giving to literacy, my interest in interaction strategies has not lessened. I think it is something in which we have to continue to do more study. We have a tendency in this field, and maybe it is an American problem, to focus on one topic and drop another one. Somehow I would hope that there would be enough of us who are more senior in the field, who would help to keep in perspective what the issues and the problems are.

I don't see us as having progressed a whole lot with regard to effective interaction. We seem to think that because we have discovered strategies this should assist in the more natural flow of conversational exchange. But in my interaction with users of our communication systems,

both with light and high technology, I'm not seeing it. The good users are still good users. I think they would be good users regardless of what techniques and strategies we gave them. Those who are not good users, remain that way, in spite of having been introduced to many strategies. I have a notion about why some of that may be. We have put much of our emphasis on the user and have not given enough education to partners. What may go on between those of us who know more about some of the strategies and who stimulate the give and take of conversation, needs to be applied with more communication partners. That is something we have to find some way of doing.

We also have to recognize individual differences among persons with disabilities. There are some who will be outgoing by nature; and some who, no matter how much we work with them, are not going to be outgoing people. They're quiet and somewhat passive by nature and so I say, allow them to be so. Who are we to invade this private territory and expect all individuals with a physical disability to perform and behave in one particular way?

Assertiveness

What I see is that the good AAC users who are literate persons are "assertive". I use the term, meaning the opposite of "helpless". Because they were more assertive and demanding they probably got more attention. They also had more self confidence and an accumulation of experiences. This was like a scaffolding for them, assisting them to have time on their communication boards, to have more time with partners, to be more demanding and to get more things. In this sense it has paid off in that we can see it demonstrated in a basic proficiency. Now it may be, and I don't know this, that they are more intelligent, but there is also that other ingredient that they come from a family that has promoted them and has made them feel good about themselves. Maybe a better way to say it is a style. There is a lot of self confidence. I use "assertiveness" rather than aggressiveness, because they're not pushy in the sense that they turn people off.

Learning is not all easy and par-

ticularly, I think, when you have grown up to expect everyone to do things for you. It's always very exciting for me to see some of our physically disabled children who do a little acting out and begin to demand. In too many cases, I feel we have not allowed our young users to help in the decision of not only what the system may be, but in what the vocabulary is going to be and where it will be placed. We go along still with the attitude saying, "Oh yes, we've done this as a team," but two major people were not present — the child (potential AAC user), and the parent. To me this is no longer satisfactory. Unless we can get a lot of input from the parent and child, then we have not put together a system that is acceptable. I don't care how acceptable it is to you and me, if it is not acceptable to the parent and the user, then let's forget it because they're not going to use their systems effectively.

Bright young professionals are surfacing. They are being challenged by the many issues that are being presented across technology, education, communication and vocation. The last will be of growing impor-

tance. How, ultimately, can we be providing for AAC users to make their contribution through good fitting of systems, through doing a much better job of educating them, through assisting them to be better interacters, if as adults, they must say, "I just want something to do?" The employment/vocational issue is a major concern, one I venture to say that is as big an issue in all of the countries as it is in the USA.

The one thing I would like to see us do in ISAAC is become more holistic in terms of our concern for AAC users. I made the statement years and years ago that what we do for the person's communication we do for the whole person. Truly it is the ground of our being. It is what allows us to do the appropriate kinds of problem solving and the socialization. It all centres around communication, and certainly if we're a discipline, and I think we're getting to the point where we are going to be able to call ourselves that because we're building a science base, then we've got to look beyond just providing an effective communication system and we have to say "for what?"

Well, for education and for a better independent life style which then includes vocational and/or professional opportunities. I see a tremendous challenge for all of us and it's a very big one. It means treading in some areas that we have never tread before, but that has never stopped us. We've just got to go on.

I am very heartened now, as I go to speak in various states, to see the large numbers of people that are working in augmentative and alternative communication. At the same time, I am discouraged because very few of those belong to ISAAC. We need to get them into the larger body. One of the big challenges in the USA is to increase our membership in USSAAC and ISAAC. With greater numbers we will have a stronger voice when it comes to influencing the legislative process as well as extending the knowledge base — which we must do for the benefit of persons who ultimately can "speak" for themselves. □

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Introducing AccessBliss

SHIRLEY McNAUGHTON

We now have software that makes Blissymbols accessible on the Macintosh computer to AAC users, clinicians, teachers and families. For those who have Macs, it opens up a wealth of possibilities! Figure 1 is a sample of what the *AccessBliss* screen looks like.

The long box across the top is the Clipboard field where the content of the Mac clipboard is displayed. As you select the symbols you wish to use, they are accumulated in the clipboard. At the right side of the display is the Find field display where you enter the gloss of a symbol or its index number and they are displayed directly below the Find field. At any one time, all the

glosses starting with one letter of the alphabet are present in the Blissymbol Gloss field at the left of the display. In the example in Figure 1, the glosses beginning with A are displayed and the symbol just selected is *apple*.

One of the valuable features of *AccessBliss* is the ease with which indicators can be changed. Although *apple* appears in the singular in the alphabetical listing, the plural indicator or any other required indicator can be added by using the *AccessBliss* pull-down menu.

AccessBliss can be used to get Blissymbols into any word processing program, another HyperCard stack, or any other Macintosh application program. The symbols can be obtained in either text or picture format. The former will usually be used within word processors, but if you wish to animate

or add illustrations to the Blissymbols, you will want them in picture format.

We are only beginning to discover the many ways in which *AccessBliss* can help us. We can write Bliss stories and letters, design worksheets, make and revise symbol displays and insert Blissymbols within the text of our writing. *StoryBliss* (described in *Communicating Together*, March, 1990), will be the first application program to include *AccessBliss*. We look forward to many more.

AccessBliss has an interesting origin. It's another one of those wonderful "World of Bliss" stories!

A "World of Bliss" Story

First, there was Dr. Peter Reich from the Department of Linguistics, University of Toronto, who has been interested in and supported

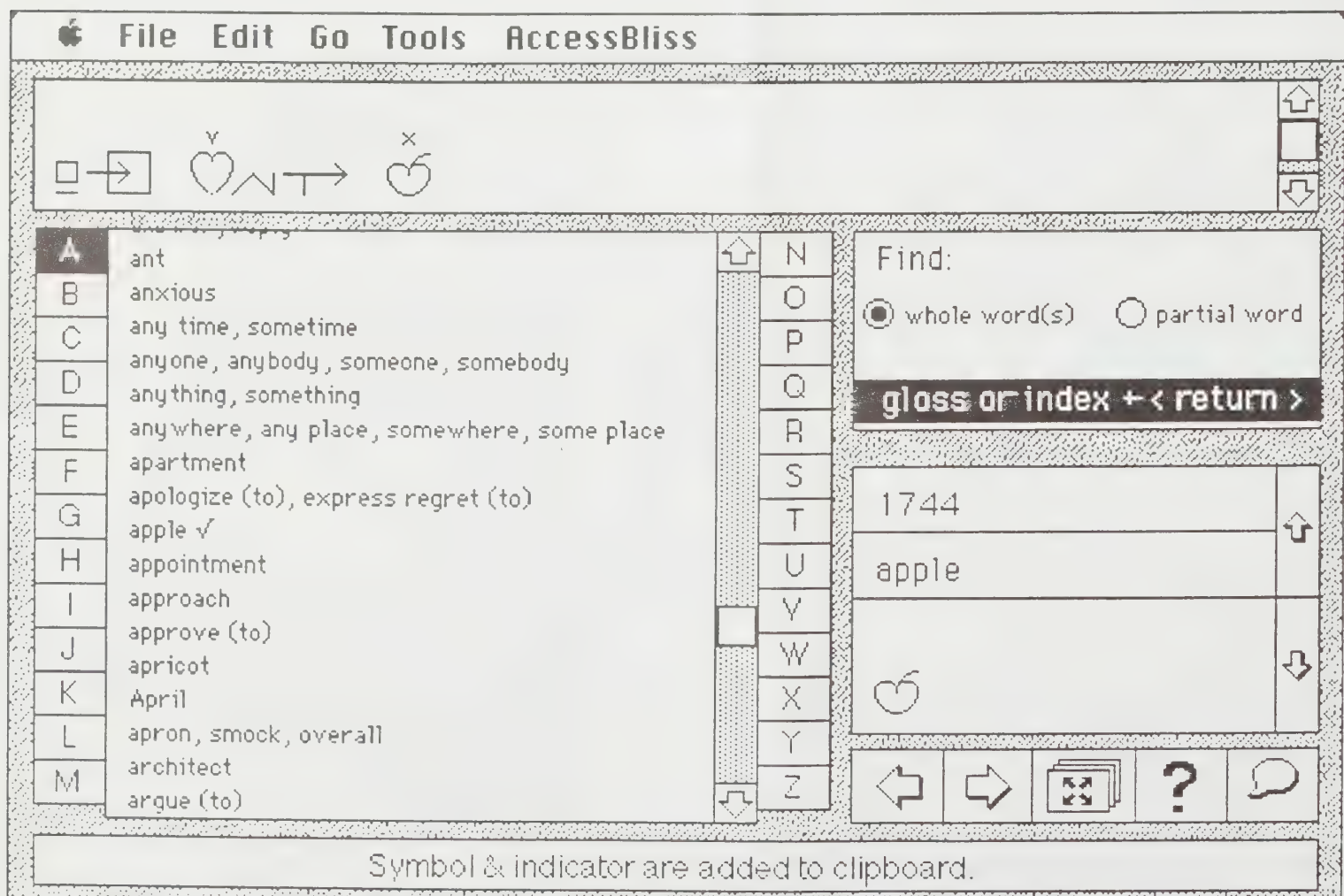


Figure 1. First Screen from AccessBliss.

the development of Blissymbolics since 1972. He was one of the contributors to *Blissymbols for Use* (Hehner, 1980), serving as linguistic consultant to the project and creating the symbol classification system for this first dictionary of Blissymbols. In 1988, when Dr. Reich became aware of the font capabilities of the Macintosh computer, he embarked upon the creation of a Blissymbol font, which became known as the *BlissTemplate Font*. Its first application is within the BlissTel Project, being undertaken by IDON Corporation, as a Supply and Service Contract, for the Department of Communications, Government of Canada. Throughout the development of the *BlissTemplate Font*, Dr. Reich was ably assisted in checking all the symbols by Claudia Wood, Jinny Storr and Ruth Harrington, from the BCI symbol office.

During the many months while Dr. Reich was refining the *BlissTemplate Font*, three different Macintosh software projects were initiated. Each contributed to *AccessBliss*.

I'll begin with *Symbol Sequencer*. In January of 1989, when I was notified that I would be invested as a member of the Order of Canada, several articles were published about the work I had done with Blissymbols. In one interview, I mentioned that I was working on a project that required computer programming and that I was having difficulty since I lacked training in programming. The article was read by Russell Galvin, a mature student at the University of Guelph who phoned BCI and volunteered to do some computer programming to assist me. Little did he know the commitment he was undertaking! During the months that followed Russell donated countless evenings and weekends to developing *Symbol Sequencer*, a program for storing Blissymbol sequences for the *Blissymbol Component Minspeak Words Strategy* program being developed for the TouchTalker™ by Annalu

Waller and myself. Of course, Blissymbols were needed within the program, and Russell developed *BlissFinder*, a HyperCard stack using the *BlissTemplate Font*.

When I approached Russell about another project, he eagerly accepted. It became *StoryBliss*, a program to assist Blissymbol users make the transition to the reading of print. It incorporated *BlissFinder* and gave Russell the opportunity to refine the work he had done previously for accessing Blissymbols in *Symbol Sequencer*. The improved *BlissFinder* had many valuable features and Russell and I were delighted at the capabilities it provided within *StoryBliss*.

The next person to become involved in using the *BlissTemplate Font* to access Blissymbols was Fraser Shein from the Hugh MacMillan Rehabilitation Centre. Fraser had been exploring the capabilities of the Macintosh and had developed a HyperCard stack which he named *BlissList*. This program, too, had many useful functions, which I discovered when Fraser gave me a copy in August. Now we had two HyperCard stacks, each with unique capabilities. As Russell and Fraser began to co-operate on upgrading their respective programs, *BlissList* and *BlissFinder* began to resemble each other more and more. As we prepared the two programs for distribution, it became evident that we needed to combine the two into one. This has been done! It is *AccessBliss*.

AccessBliss is the result of extensive volunteered work of Peter Reich, Russell Galvin and Fraser Shein. We are proud to introduce this user friendly Blissymbol HyperCard software for the Macintosh!

For further information, contact: Katherine Seybold, Blissymbolics Communication International, 250 Ferrand Drive, Suite 200, Don Mills, Ontario, Canada M3C 3P2.

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Blissymbols used herein are derived from the symbols described in the work *Semantography*, original copyright © C.K. Bliss, 1949.

September 1982, C.K. Bliss granted an exclusive, non-cancellable and perpetual, worldwide license to the Blissymbolics Communication Institute, to provide standards for the application of Blissymbols, for use by handicapped persons and persons having communication, language and learning difficulties. In 1987, the Institute was renamed Blissymbolics Communication International.

CATHY FAIRLEY

The Paraphrase is written for those who are moving into traditional orthography. It offers an independent reading opportunity for the growing reader. The Paraphrase is written by Cathy Fairley, former consultant, Easter Seal Communication Institute.

Communicating with our Forgotten Future Generation

Paul Marshall is twenty-six years old. Once a week he goes by bus from his home on a farm to Toronto. Every Thursday he helps at the Evergreen drop-in centre on Yonge Street. There, he works with teenagers who are in trouble.

* * * * *

Toronto is a big city with lots of kids. Many have no homes, and 15,000 live on the streets! They have been forgotten by others.

I always wanted to help others, but I can't talk. I have cerebral palsy. I use a Blissboard. I didn't know how I could be a social worker or a counsellor. But now I work at a mission in Toronto. Every week 600 kids come in.

These kids need friends. They need people to spend time with them. I play games with them. We talk and laugh. We listen to each other.

These kids need to know that people care about them. Now I know that I can help them even if I can't talk. You can say a lot to others in many ways. Communication is more than just talking out loud!□

To Readers of Paraphrase

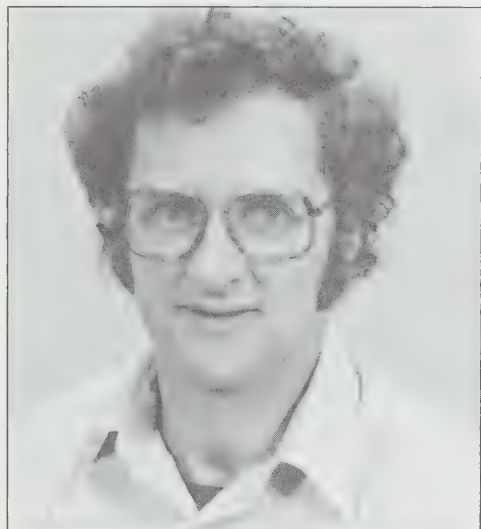
This story is from Paul Marshall's original article that appeared in *Communicating Together* Volume 8, Number 1, March 1990.



Paul Marshall with his friend John.
Photo by Carol Lynn.

From Patients to Consumers: The De-institutionalization of Rehabilitation

GEB VERBURG



"Research and Publications" is written by Geb Verburg, who has been involved in the field of nonspeech communication since the mid-seventies. A cognitive scientist, Mr. Verburg is currently working as a research associate in several projects at the Hugh MacMillan Rehabilitation Centre, Toronto.

Speaking for Canada, and maybe for all of North America, I believe that there are powerful dynamic forces at play which are about to change the face of medical services, beginning with rehabilitation services. The strong forces that create the tension in the rehabilitation and AAC service field are first, the incredible costs of services (8 to 10% of Gross National Product in Canada and the United States respectively) and secondly, the growing empowerment of persons who are disabled and/or their parents.

The skyrocketing cost of medical care helps to soften up the institutions and organizations, and drives the hierarchy of power to look for cheaper alternatives. Through various fiscal pressures, the health care and rehabilitation systems are getting ready for change. It would be unwise and imprudent for us not to

be involved in this changing.

An empowerment or increase in awareness of their role has slowly taken place in our clients and parents. For the longest time our patients have balked at being called and treated as patients. Being called patients and treated as patients who are ill and necessarily dependent persons, as is common in an acute care hospital, is not justified by the needs or clinical condition of the persons who require rehabilitation services. A person who is disabled is not sick, ill, or diseased. And if there is anything our clients do not need it is an increased dependency. To address our former patients as clients is really not much better since the word "client" still retains an implicit difference in standing; with the client being less in-the-know than the professional.

In addition to these two main dynamic forces there is a fine collection of paradoxes or contradictions that exists in today's society. For example, even though all our health ministers are professing that too much is spent on medical services there are very few hospitals in Toronto, for example, that have not either just completed, are currently building, or are about to build a major new or expanded facility. It takes less than grade two logic to realize that larger hospitals will require larger budgets.

For rehabilitation services, I believe that we should very seriously ask the question: "Do we need centralized service institutions?" I think not, certainly not the ones that have clients come to receive services; but I'll come to that later.

The Lack of Fit of the Medical Model

If we listen to the persons whom we are to serve and take their needs into account, then we should abandon the medical model. Our consumers are not sick or diseased, they do not need to be cuddled and cared for, instead they must learn to be independent, to stand on their own two feet, to speak for themselves. That, at least in Canada, persons with a disability still fall under

medical jurisdiction and funding, is immediately counter-productive. A person who wishes to be (come) independent and wants to be considered as being as healthy as the next person, is not helped in these efforts by an archaic and expensive health care ideology that is in urgent need of change.

Earlier I indicated that I did not believe in the continuation of rehabilitation centres as we know them now. I say this because I believe that there is almost no service, intervention, or assessment that could not be performed at a place other than the old centralized rehabilitation centre. AAC intervention, mobility training, therapy, or technology prescription could all be done, for example, at home, school, or at a health maintenance centre or community hall. Perhaps the services could even be performed better at home, certainly with less cost (time, lost work, travel, missed school) to the family than traditional visits to the rehabilitation centre.

One of the strongest justifications for the old-fashioned centralization of medical intervention facilities is the expense of the equipment and the degree of specialization of the persons using and maintaining it. That argument does not apply readily to AAC and other rehabilitation services. A non-portable multi-million dollar tool would justify transporting people to the tool rather than the reverse. Neither in AAC nor in therapy, psychology, social work, or even engineering are the tools such that they cannot be made portable.

I know that we profess to empower the people we serve, but even making a person travel for the benefit of being served by us is of course a very clear indication of where the power lies and where not. It will take much strength and broadmindedness on the part of the AAC and rehabilitation professionals to give up this power and to start to serve as equals. The consumers of rehabilitation services are, after all, equally independent, more directly responsible for their health and well-being, and should — if we do our job well — be as self-reliant in

all activities as is possible.

It happens less often than say four years ago, yet I am occasionally struck by incompatibilities that exist in a rehabilitation or AAC service environment. I think that there are still clinicians who feel that the clients have infinite time, resources, energy, and no job, no meetings, no trips, or no appointments to keep and can therefore be asked to come to the centre whenever the clinician deems best. You know that this is not so. Almost all parents have (must have) a job and taking time out from that job to attend clinics, AAC, or therapy sessions is as difficult as it is for you to stay home with a sick child or to leave work for any other reason.

Practical Implementation of Rehabilitation/AAC Consumerism

What might this new rehabilitation and AAC service world look like if we follow the lead of democratic consumerism? First of all the services that are now still dispensed at centralized service facilities will have found their way into the community, either by professionals setting up private consulting services, or working for commercial rehabilitation technology stores. Schools, school boards or school districts may employ direct or consultative services from professionals, as may large or mid-sized companies. Other professionals will be working in health maintenance centres, acute care hospitals, or in mobile clinics. The integration of persons who are developmentally delayed into society and into the school system can serve as an example of how professionals are reabsorbed and how effective this integration of clients and professionals has been.

For persons with a disability, the services become accessible in different places, with possibly a greater amount of choice. With that greater choice will come a greater amount of responsibility or onus on the customers for the quality of their choices. In practical terms it would mean that people who are disabled could go to a specialty shop to look at and try out voice output devices, or wheelchairs, or prostheses. It would be essential that these stores had expert help, and an ample selection of each of the devices or at

least video materials showing and explaining the options.

A free-market system might work very well. It will almost certainly work for a fair percentage of current device users. The old adage of "customer beware" will apply in full force, but that is no different from any other store or major purchase. However, it is a real-world situation; it is a form of independence and responsibility, and I think that is worth a great deal.

A Case for Some Form of Centralized AAC/Rehabilitation Units

If we begin with the premise that AAC services and rehabilitation services are provided, made available, or are sold to persons who need these services, in places that are as convenient as possible for the buyer/seller (market place dynamics) then do we still need centralized rehabilitation facilities?

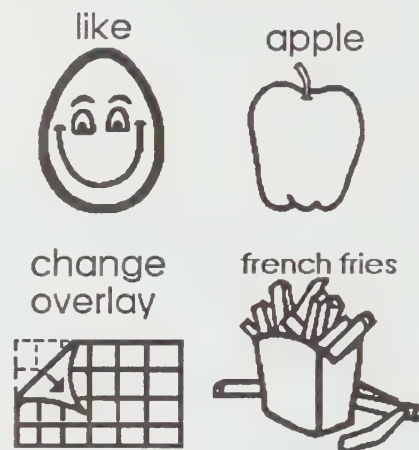
The service role of the central AAC/rehabilitation clinic can probably be spread over the different structures of a community. And with the proper care and consumer-know-how, persons who are disabled could go out (phone-out, fax or confer-out) and buy the services they want and need. But is that all that the centralized institutions now provide? No, there is indeed more that occurs now in the AAC and rehabilitation centres which is essential to the growth of the field and to the quality of service.

The following functions are provided much better at centralized facilities:

- Education and training of current and future professionals
- Research and development of existing and new programs and treatments
- Development of new technologies

Each of these is essential to the growth of the effectiveness of rehabilitation services and requires a congregation of different professionals and parents and customers all addressing the same practical problem. Individuals scattered over the community cannot perform these three functions, and without research, education and development the field will stagnate and regress. □

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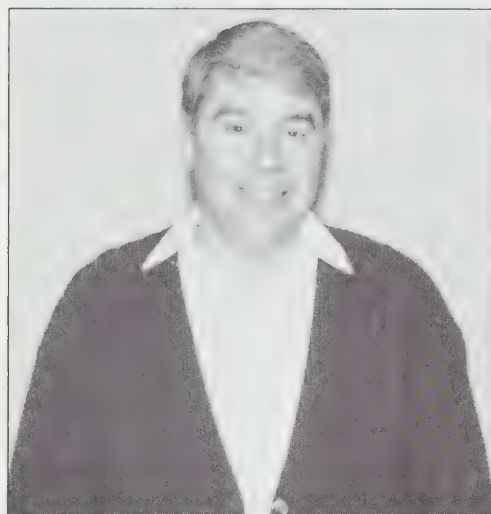
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A Case Study of a Course on Empowerment and Disability

PETER LINDSAY



Dr. Peter Lindsay is a professor in the Department of Special Education at the Ontario Institute for Studies in Education (OISE). He has been active in the field of augmentative and alternative communication for many years, and serves as chair of the Operations and Administration committee of the International Society for Augmentative and Alternative Communication (ISAAC). Dr. Lindsay is chair of the Communication Advisory Committee of the Easter Seal Society (Ontario) with the prime function of guiding the development of programs and policies within the Easter Seal Communication Institute (ESCI). He is a member of the board of directors of the Easter Seal Society (Ontario) and of its executive committee.

In the following article Dr. Lindsay describes a unique course now offered at OISE.

The training of "helping" professionals

I am associated with the Department of Special Education at the Ontario Institute for Studies in Education (OISE). As the graduate department of education for the University of Toronto, we provide masters and doctoral training for individuals working with disabled students in Ontario schools. Our

students therefore are special education teachers, educational consultants, speech pathologists and occupational and physiotherapists who are involved in one way or another with Ontario students who have cognitive, emotional or physical disabilities.

For many years, our basic program involved a set of "core" required courses covering a common knowledge base and basic set of skills that the department feels all professionals working with disabled individuals should have. What was missing from our core program was any course that required the developing professional to come to grips with the human side of disability. That is, in addition to the more technical training, we wanted our students to understand the barriers to empowerment that these individuals must face on a daily basis, and to obtain first hand experience, to the extent possible, of what impaired individuals are up against as they attempt to overcome or deal with these barriers.

Last year, another professor in our department, Iain Davidson, a former doctoral student, Janice Light, and I, decided to try to provide such an educational experience. We mounted a special topics course called *Empowerment and Disability*. All of us found it to be a rewarding experience and felt, in fact, that it was so worthwhile it should be considered as a mandatory part of the professional training at OISE. What follows is a description of the course and a discussion of some of the more basic issues that were raised.

One of the important aspects of the class was its composition. A third of the students had some sort of disability. One was physically impaired; one was deaf from birth; a third was deafened and legally blind. Others were intimately acquainted with disability through one of their own family members: one had a cognitively impaired son; another had a blind fiancé. Thus, the class members themselves brought a wide variety of perspectives and viewpoints and a great deal of realism and practical experi-

ence to our discussions.

Major Assignment

The major assignment in the course was a case study of a disabled individual. Each student had to contact someone with a disability and work with that person throughout the duration of the course. The primary objective of establishing such a relationship was neither a clinical nor a professional one. Instead each student had to try to identify the major barriers to empowerment that his or her partner was facing on a day-to-day basis. In collaboration with his or her partner, the student had to determine the primary sources of empowerment and disempowerment in that partner's life.

At the end of the course, the students were required to write up the case study outlining their partners' experiences and their interpretation of those experiences. We plan to publish a selection of these cases as a resource book for future offerings of the course. Compared to traditional case studies, the case studies produced in this course had a critical and exciting feature. Prior to presenting in class, the students were expected to discuss their cases with their partners to make sure the latter were aware of how the students were interpreting the various events in the partners' lives. The partner was thus treated as a true collaborator in developing and interpreting the case. If the partner did not agree with some of the student's interpretation, the latter was expected to report that disagreement. This arrangement is equivalent to letting a patient read his or her own case file and to participate in interpreting the information in that file. It provoked a good deal of debate about the appropriate role of a professional as a dispenser of knowledge, as well as the "clients'" rights to the information gathered about themselves, and the kinds of role the "clients" should play in setting educational, and rehabilitation goals and in deciding on the approaches to be taken in their own programs.

Choice of partners

In establishing the partnership mentioned above, it was the students' responsibility to decide on the type of disability they wanted to investigate, to establish the relationship with an individual of their choice, and to work out the most appropriate pattern of interaction with that person. The range and the diversity of partners the students chose was striking. Given that most of the students in the course were involved in education in one way or another, it was somewhat surprising to us that most chose to work with adults rather than with school aged children. Yet, almost every type of major disability encountered in schools was represented in at least one person's case. One chose an individual about her own age who was able to communicate only through an alphabet board or computer. Apparently the motivation for this choice was that, towards the end of his life, the student's grandfather had lost his ability to communicate and the student became the primary communication intermediary between her grandfather and the medical staff and other family members. Ever since this experience, the student has had a particular interest in the ways in which the loss of communication disempowers an individual.

Another student worked with a young schizophrenic woman because emotional problems had always been an interest of hers. A third chose as her partner her own twenty-one year old son who had profound cognitive impairments. Over the years, the educational "professionals" who were advising this woman had recommended diametrically opposed educational programs for her son at least three different times. What is more, they persisted in blaming her for not knowing which ones she should have paid attention to and which she should have ignored. Still another student who was profoundly hearing impaired herself chose two partners both of whom were also hearing impaired. One was a congenitally deaf man in mid-life who was ostensibly not disempowered at all by his lack of hearing. The second was a young woman in her twenties who had recently lost her hearing to a progressive hereditary disease. She was still at

the stage of denying she had any difficulty at all, a denial that was most compellingly demonstrated when the student and her partner went out for coffee. Rather than admit to a problem in communication, the woman ate a hamburger mistakenly brought to her when she tried to order a cup of hot chocolate. A student visiting from Japan chose a blind partner in part because she was engaged to a blind individual in Japan. One of the more interesting choices was a cognitively impaired woman in her eighties. Unlike most us, this woman was finding that the aging process was, in itself, empowering. People expect old people to lose their cognitive functioning. Hence aging for this woman was empowering — she was becoming more and more "normal" as she aged.

Finally, one young student in the class who had acquired a progressive spinal tumor in her twenties that reduced her mobility to the point that she needed to use a wheelchair, made a particularly poignant choice. She chose as her partner a young mother whose husband had just been killed in a car accident in which she had become quadriplegic and her two infant children had been severely injured. The mother was in the process of trying to come to grips with the prospect of raising her two young children from a wheelchair without her husband. The student was trying to come to grips with the permanence of her own disability in relation to the potential recovery of her partner.

As might be imagined, the students' discussions of their partners and the relationships as they developed provided a rich and provocative database for considering a wide variety of fundamental issues related to disability and empowerment. Moreover, the range of disabilities and ages involved in the different cases was broad enough to identify the kinds of issues in empowerment that transcend specific types of disabilities and age groups. By way of illustration, I will consider two of these themes next.

What's in a Name?

One of the first issues we tried to come to grips with in the course was the issue of terminology. Given

that the language we use is an important contributor to the attitudes we hold, what are the correct labels that should be used to describe those who are different? Are the people we work with more properly called *disabled*, *impaired*, or *handicapped*? Should they be considered to be *retarded*, *developmentally delayed* or perhaps *severely challenged*? The labels keep changing as we attempt to introduce a new more neutral term to replace an older one that has acquired a derogatory connotation, only to find the new term also soon becomes negative. Or sometimes we end up with a term that is so ambiguous it fails to communicate anything at all. Perhaps we should stop using labels altogether? Even an apparently innocuous distinction such as calling someone a *client* rather than a *student* can have an amazingly powerful effect on how we, as professionals, view and "treat" that individual.

Perhaps the most sensible path through this linguistic maze is the one charted by the World Health Organization (WHO). According to this scheme, three basic terms should be distinguished. The first term is *impairment*. This is a specific breakdown in bodily or mental functioning that is a direct result of some sort of disease process. Thus the disease process of glaucoma produces an impairment in visual functioning. Similarly, the disease process of cerebral palsy produces an impairment in motor functioning and control. Downs syndrome produces impairments in cognitive functioning. The impairments are the given in the situation. They are a direct result of some sort of disease process that may or may not be treatable medically.

According to the WHO definitions, depending on the circumstances, a specific impairment may or may not lead to a *disability*. The important thing is to distinguish between the impairment which is constant and always with the individual and the disability that varies according to the context or situation. It is circumstances that disable the individual with an impairment. The limited time and print focus that are typically associated with testing in schools, for example, will almost certainly disable a learning disabled individual who has a special problem

with print processing. However, the school (and the clinic for that matter) can remove or reduce that disability by using auditory testing and untimed test situations. Nonspeaking physically disabled individuals are usually disabled in most face to face communication situations where speed is a factor even if they have some sort of alternative or augmentative communication device. Provided they are literate and have sufficient time to prepare, however, the same individuals may perform totally normally when communicating in print for a school essay or over an electronic network where they are able to formulate and respond to messages at leisure. In fact, when communicating over a network, they even have the luxury of deciding whether or not others on the network should know about their impairments. It is important to note that in none of these cases is it the impairment that is being changed. The student with an impairment is being disabled by one or another feature of the environment and it is therefore the job of the teacher or clinician to identify what it is about the environment that is disabling the student or client and to alter it so that the latter is empowered to show his or her potential.

The final term in the WHO schema is the term *handicap*. This is the social definition of what the society considers a person is or is not capable of doing. The intriguing aspect of the notion of handicap is that, at any given time, the type of limitations and the capabilities associated with any particular impairment differs from society to society as well as, over time, within the same society. The Japanese society, for example, believes that blind people are particularly adept at massage therapy and so they are trained at school to be massage therapists. North American society, on the other hand, believes that blind people have particularly acute hearing and hence make good piano tuners. We also apparently believe that deaf people are especially capable of sorting mail perhaps because we assume that the noise levels in many postal plants will not bother them.

The point to be made is that the way in which we as a society handicap an individual with specific impairments does not seem to have

much relationship to the actual nature of the impairment. These social stereotypes of various handicaps, however, do profoundly effect how society will train a person with impairments and hence what his or her range of employment opportunities will be. Often society or even schools decide that the handicap is such that an impaired person is not capable of doing anything and hence is unwilling to provide any training at all. Society's definition of handicaps has a profound impact on the empowerment of impaired people in the employment domain.

What conclusions can we draw from this brief excursion into the linguistics of disability? Whether we are speech pathologists or educators or occupational therapists, as professionals we must be constantly aware of the ways in which we unintentionally disable or handicap the people with whom we work. The disempowering impact of others' definition of a person's capabilities was particularly well illustrated by one of the partners in the course. The young woman in question was profoundly impaired by cerebral palsy, required a wheelchair for mobility and a full-time attendant for feeding and personal care. She used a language board for face to face communication and a computer for print. Using a modem, the partner in question managed to sign onto a local bulletin board where she greatly impressed the other bulletin board users with her poetry and corny jokes. She impressed them that is, until some of the other users found out that she had cerebral palsy, was wheelchair bound, and could only communicate with the aid of assistive devices. From that point on, even though they had never seen or met her face to face, the societal definition of the physically disabled took over and completely changed the tenor and nature of their communications with her. Her only escape from this handicap was to terminate her interactions under her real name and sign on again under a pseudonym.

The role of the professional

Giving away what you know: How many of us in our work with impaired people have as our pri-

mary goal working ourselves out of a job? Do we really try to give away our trade secrets so that an individual will be empowered to take on as much responsibility as possible for his or her own life? A second major and recurring topic of discussion in the course was the proper role of professionals working with impaired individuals. The students with impairments in the course tended to be the most vocal on this topic. Most of them stated unequivocally that the only proper role for professionals in the helping professions was one in which the client was treated as an equal partner in defining treatment goals and approaches. Perhaps the tenor of their discussion is best captured in the rather extreme statement by one of the most adamant of the class's patients' rights advocates: "I think it is only fair that if my doctor expects me to strip, he or she should strip first."

Being a paid friend: A second aspect of the role of professionals was whether it is proper for a professional to serve as a paid "friend" for his or her client. Many professionals would probably state that it is entirely inappropriate for a professional to be a friend of a client. Indeed, one of the edicts on many professional training programs, is that it is unethical and may even be grounds for revocation of one's license. On the other hand, one of the most problematic things about being impaired is that the normal pattern of personal relationships is usually severely distorted and hence impaired people are particularly vulnerable in this area. Most of us have family to whom we are very close, and a large group of friends with whom we have varying amounts of contacts. Once in a while we may have dealings with a professional, whether a doctor or a dentist or perhaps a psychiatrist, to help us with specific problems. The person with impairments, on the other hand, may have only two of these three categories of relationships. The first is the family and relatives who, because of family ties, are more or less obliged to be with him or her. The second is the relatively large number of professionals who are paid to be with him or her. What is missing is the close circle of friends.

This distortion in the usual pattern of friendships tends to put a very special burden on the professional relationship. To what extent are we, as professionals, concerned with empowering the individuals with whom we work, obliged to fill in the circle? Are we responsible for attempting to substitute for the lack of friendship relationships in the impaired person's life? What about the fact that establishing such a personal relationship runs counter to the strongly held tenets of most traditional training programs? Can we afford to ignore the fundamental gaps in the social life of the impaired person and expect anything like full empowerment? These issues generated lively and intense debates about the basic roles and respon-

sibilities of professionals who seek to help empower those with whom they work. Unfortunately they did not generate a consensus on the most appropriate answers to the questions posed.

Conclusions

The above description can only give a flavour of the kinds of issues that were addressed and the sorts of discussions that ensued. In the contexts of the various cases, many other topics were discussed and analyzed such as the relationships among the concepts of power, ability, and empowerment; the characteristics of families, the home and the school environments that are most conducive to empowering

individuals with impairments; the impact of impairments on family and significant others, particularly siblings; the differences in the adjustment problems of people who are impaired from birth and those who acquire their impairment later in life. These are the issues that are important for all professionals to debate and the course provided a very flexible and meaningful format for discussing them. According to the students, however, the most powerful feature of the course was the opportunity it provided them for obtaining some insight, however fleeting, into the life and mind of an individual with impairments. □

MACHINES, COMPUTERS AND THINGS

AAC with ALS — A Personal Story

LOWELL BOSTWICK

Adaptive Communication Systems (ACS) recently conducted its annual essay writing contest. Lowell Bostwick was one of the first prize winners with the following article about the difficulties he faced with his disabilities as a result of amyotrophic lateral sclerosis (ALS), and the technology that helped him overcome some of his communication problems.

Two very ingenious products, acquired through Adaptive Communication Systems Inc. (ACS), have absolutely revolutionized my life. I have enjoyed using my computer access program, Words + Screen Keyboard Emulator (WSKE, pronounced whisky) for a year and a half. I also make excellent use of the recently received AAC system Equalizer II. Both these single switch accessible aids have benefited me greatly in different ways.

First, let me tell you a little about myself. I am a thirty-three-year-old man disabled by amyotrophic lateral sclerosis (ALS). ALS is a terminal neurological disease of the nerves supplying the voluntary skeletal muscles. The disorder is characterized by progressive muscular weak-

ness and atrophy including the muscles involved in speech. ALS does not affect the involuntary muscles, eye muscles, or intellect.

I am a truly atypical victim of ALS because of my early age at the onset of the disease, and my very long survival. I was nineteen at the time, and after fourteen years I am quadriplegic and virtually without a voice. Over the past several years, my voice has gradually declined in quality to the point where I am intelligible to just a few family members, and only then with much effort by both parties. Becoming non-vocal has been by far the most devastating, most isolating effect imposed by this cruel disease.

My world began to open up in May, 1988. That's when I received WSKE, the computer keyboard emulator. Suddenly, I was able to access the endless possibilities that computer technology offers. The single switch version of WSKE was so easy to use, I was soon using many conventional computer programs.

Using WSKE and word processing programs, I regained the long lost ability to write. Other readily available software enabled me to draw, do a spreadsheet, create graphs, and the list could go on and on. With the addition of a modem and using the phone line, much of my isola-

tion has been lifted. Many new friends were met through local electronic meeting places, called BBSes, and through online information services such as CompuServe.

While I was gaining much from computer use, I became increasingly estranged from my family. Even worse, my younger nieces and nephews were growing up without every truly getting to know me. I was shortsighted in not equipping WSKE with a voice synthesizer. The effortless nature of simply listening, and not being forced to stop and read, is an important consideration for the recipient of the communication.

This mistake was remedied somewhat when I received the more capable WSKE II, this time complete with Smoothtalker voice synthesizer. As much as WSKE and later WSKE II helped me, I realized that I needed an easier, more spontaneous means of communication. The answer the Equalizer II.

Although WSKE II is a godsend in its own right, I employ the Equalizer II system, also fortified with Smoothtalker, for most of my communication needs. Credit goes to this incredibly easy-to-use aid for making my communication troubles largely a bad memory. The Smoothtalker voice synthesizer is easily understood by all. I am silent no

longer!

WSKE II operates as an access aid to standard computer software by displaying a small scanner in the upper right corner of the screen. Through a proven time saving scanning technique, the desired key is selected from easy to read menus. Projected next to the scanner are six spelling completion or adaptive prediction words to accelerate typing speed. Users simply select the next word from the six most likely words as they spell or the program actually predicts the word before they type, from learned writing patterns.

Other convenient features include automatic capitalization, word endings, and punctuation spacing. Abbreviation expansion allows for long phrases to be created by short strings of letters. Two modes of speech output can be used while running another program. On-line help is available in a context-sensitive manner. It is not easy to do adequate justice in describing this aid with mere words. Suffice to say, WSKE II is a joy to use.

Equalizer II is a powerful assemblage of many integrated features in a speed enhancing format. Writing/word processing, drawing, music, games, and "talking" capabilities are incorporated in one easy to use package. Since it is a complete, stand alone program, the entire computer screen is utilized. Full

screen scanning provides an even easier selection method. This device has many of WSKE II's features, and then some. As with WSKE II, Equalizer II is tough to describe with just words. All in all, it is an unbeatable augmentative communication system!

Although I have access to many fine conventional word processors via WSKE, I prefer to use Equalizer II for writing. It is simply easier and faster than standard word processing programs. I use WSKE II for computer specific tasks such as minor programming, spreadsheets, and modem use. In my years long investigations, I have found those two packages, both manufactured by Words+ Inc., to be the most functional and cost effective, single switch accessible systems available for my specific situation.

SmoothTalker voice synthesizer's true beauty lies in its simplicity. It's a software based voice synthesizer that enables your computer to take the place of the normal hardware, except for a small speaker. Wonderful for portability, less to malfunction, and therefore ideal for me. Its high quality voice output may be manipulated for speed and pitch by the user to suit personal taste. As I alluded to before, it is understood by those with whom I communicate, and was quickly accepted as my own voice. I have found that the novelty value of synthesized speech

rapidly erodes and people listen to *what* I say, as opposed to *how* I say it.

Directing my home health aide and communicating directly with my doctors and other health care professionals are some of the more obvious benefits of Equalizer II and WSKE II. The same applies to conversing with family and friends. Computer use has been both a useful and entertaining diversion. The technology has done much to enhance my well being and improve my level of independence.

The benefits of my devices are in no way limited to myself. They provide some welcome relief to those I have come to rely upon for the tedious task of deciphering what I'm saying and then translating it for others. Family members are also freed from the arduous job of transcribing my feeble utterances into pieces of correspondence. Naturally, I am now a much more responsive and interesting person to be around.

People are astonished to see the devices in action. They assume that I must be quite knowledgeable about computer technology — not true. Even though I have picked up a few pointers in the last year and a half, it was incidental. You need absolutely no computer experience to use Equalizer, and WSKE demands only what you desire to learn. Both systems have a negligible learning curve, a testament to the clear and logical way they are laid out. Easy to follow "plain language" manuals are included.

I look forward to mounting my laptop based system on a power chair I have on order. Imagine being able to talk outside, on the roll, or at the dentist's office! I also anticipate utilizing the environmental control feature for even greater independence. I am in good shape now, and the future looks even better.

My oft given advice to others who haven't yet taken advantage of an assistive communication device is: *Don't wait!* Compared to my life now, my existence prior to getting "computerized" was dull and uninteresting. I am grateful that those dreary days are long over. Yes, communication devices have profoundly improved the quality of this man's life! □

COMMUNICATION OUTLOOK

Communication Outlook is an international quarterly offering a multi-disciplinary source of information on the latest products, and research & development in augmentative and alternative communication.

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Control of Computer-Based Technology for People with Physical Disabilities: An Assessment Manual

KATHY S. LEE and DEBRA JAY THOMAS

Today's technology allows alternative methods of controlling household appliances or computers, and of using powered mobility. In order to maximize this benefit, it is important to approach the assessment of alternative control methods logically and systematically.

An assessment manual on this subject has been written by Kathy Lee and Debra Jay Thomas with three goals in mind.

- 1) To outline a systematic, useful assessment process for determining the optimal method(s) for clients with physical disabilities to control computer-based technology. The assessment process is very complex and there is a myriad of variables for consideration.
- 2) To improve the assessment, prescription, and personalization of the methods that disabled people may use to control technology. Use of this manual will help to increase the efficiency of the assessment process by decreasing the time involved in non-client-directed activity, such as documentation and problem solving.
- 3) To educate professionals involved in rehabilitation, and in technical manufacturing and design. While the assessment procedures outlined have been designed specifically for use by a team involved in providing technology to individuals with disabilities, the manual has been prepared to share information more broadly. Attempts have been made to limit the use of jargon and to define clearly the terminology specific to access.

This manual is the result of a three year project, funded by IBM to the Hugh MacMillan Rehabilitation Centre and the University of Toronto.

Available from:

Manager, Mail Marketing
University of Toronto Press
10 St. Mary Street, Suite 700
Toronto, Ontario, Canada M4Y 2W8
Soft cover, 309 pages
ISBN 0-8020-6695-X
Price: \$50.00

Augmentative Communication Series

The Psychological Corporation announces the publication of the *Augmentative Communication Series*, four software programs developed by Howard Shane, Ph.D., Director of the Communication Enhancement Clinic at Boston Children's Hospital. All operate on Apple II Series or compatible computers.

• Message Maker-KeyBoard

Designed for use by individuals whose motor control is only slightly to moderately impaired. *Message Maker-KeyBoard* offers more advanced users keyboard access to communication. Users should be able to structure sentences and have some knowledge of spelling rules to operate the program. *Message Maker-KeyBoard* can be used with a regular computer keyboard or an alternative keyboard.

• Message Maker-Scan

Message Maker-Scan is intended for individuals with restricted motor control, but who are able to operate a single switch activation device. The type of switch and its placement may vary, depending on the individual's needs.

Otherwise, the program is comparable to *Message Maker-KeyBoard*, because it allows users to create messages by combining stored words and phrases previously programmed by a caregiver. *Message Maker-Scan* maintains an alphabetical list of words and twenty-six alphabetical categories for storing phrases. The program's memory capacity is about 1,500 words and 300 phrases.

• Scan and Speak

Scan and Speak is the most flexible of the programs and can be customized with many options to meet the needs of an individual with physical or intellectual limitations. This software allows the caregiver to program single words, phrases, and even paragraphs for unlimited customization of messages. The messages can be organized by topics, situations, and settings.

• Touch and Speak

Touch and Speak requires the user to touch a keyboard or PowerPad (electronic communication board with a membrane surface) to activate the speech synthesizer. This easy action allows the user to access up to 615 messages pre-programmed by a caregiver, and to spell and combine words or phrases into an unlimited number of new messages.

The PowerPad may be covered with a picture overlay, which allows the user to access a message without having to read.

Touch and Speak is ideal for individuals with more severe physical or intellectual difficulties that limit their communication skills. Those with cerebral palsy, hemiparesis, and developmental delays will benefit from *Touch and Speak's* easy operation and voice synthesis.

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SCHEDULE OF EVENTS

ESCI Special Interest Seminars

In Toronto, Ontario

The Easter Seal Communication Institute (ESCI) holds a series of seminars throughout the year on a variety of topics related to the application of augmentative communication.

The schedule of dates and topics being offered in the fall is presently being finalized. Topics to be presented in the fall of 1990 include:

- Programming for the augmentative communicator in the pre-school setting
- Programming for the augmentative communicator in the school setting
- Reading for the nonspeaking child
- Basic Sign Language for use with augmentative communicators (6 week evening course)

Blissymbol Courses

- Blissymbol Elementary Workshop, May 28-30, 1990
- Bliss in a Day, Thursday, October 11, 1990

To register for seminars, or to be added to the mailing list for notification of the fall schedule, contact: Training Coordinator, Easter Seal Communication Institute, Suite 200, 250 Ferrand Drive, Don Mills, Ontario M3C 3P2
Telephone: (416) 421-8377 ex. 2205
Fax: (416) 696-1035

28th Annual Conference Canadian Rehabilitation Council for the Disabled

In St. John's, Newfoundland

- June 6-7, 1990
- "Rehabilitation for the '90s — Increasing Options, Increasing Values"

Contact: Deborah Loosemore, Canadian Rehabilitation Council for the Disabled, Suite 801, 45 Sheppard Ave. E., Toronto, Ontario M2N 5W9
Telephone: (416) 250-7490
Fax: (416) 229-1371

RESNA '90 13th Annual Conference

In Washington, D.C.

- June 15-20, 1990
- "Capitalizing on Technology"

Contact: Susan P. Leone, Mtgs Director, RESNA, Suite 700, 1101 Connecticut Ave. NW, Washington, D.C. 20036 U.S.A.
Telephone: (202) 857-1199
Fax: (202) 775-2625

ISAAC Regional Conference

In State College, Pennsylvania

- July 25-27, 1990
- "Beyond the Basics"

Fourth annual augmentative and alternative communication retreat sponsored by ISAAC and USSAAC.

Contact: Susan McCloskey, Pennsylvania ADC, 150 South Progress Avenue, Harrisburg, PA 17109 U.S.A.
Telephone: (717) 657-5840

York University Summer Course Alternative and Augmentative Communication

At York University, North York, Ontario

- July 3-13, 1990
- Lecturer: Shirley McNaughton

Contact: Office of Programmes, Faculty of Education, York University, N801 Ross Building, 4700 Keele St. N., North York, Ontario, Canada M3J 1P3.
Telephone: (416) 472-3955

Fourth International ISAAC Conference

In Stockholm, Sweden

- August 12-16, 1990

Contact: The Institute for Integration, Norrmalmstorg 1, S-111 46 Stockholm, Sweden

Technology Classes at Summer Camp

In Georgetown, Colorado

- July 15-20, 1990

Two camps are being offered at the same time: one camp is for augmentative device users, siblings and professionals who work with them. The second camp is for adaptive firmware card users and professionals or parents who work with them.

Contact: David Schmitt, Director, Center for Adapted Technology, Colorado Easter Seal Society, 5755 West Alameda, Lakewood, CO 80226 U.S.A.
Telephone: (303) 233-1666

About the Publisher

The Easter Seal Communication Institute (ESCI), formerly the Blissymbolics Communication Institute, has worked since its inception toward enhancing the lives of nonspeaking people. Now operating as a department of The Easter Seal Society, Ontario, ESCI focuses on supporting augmentative communicators and their families and the professionals who work with them through its strategic goals.

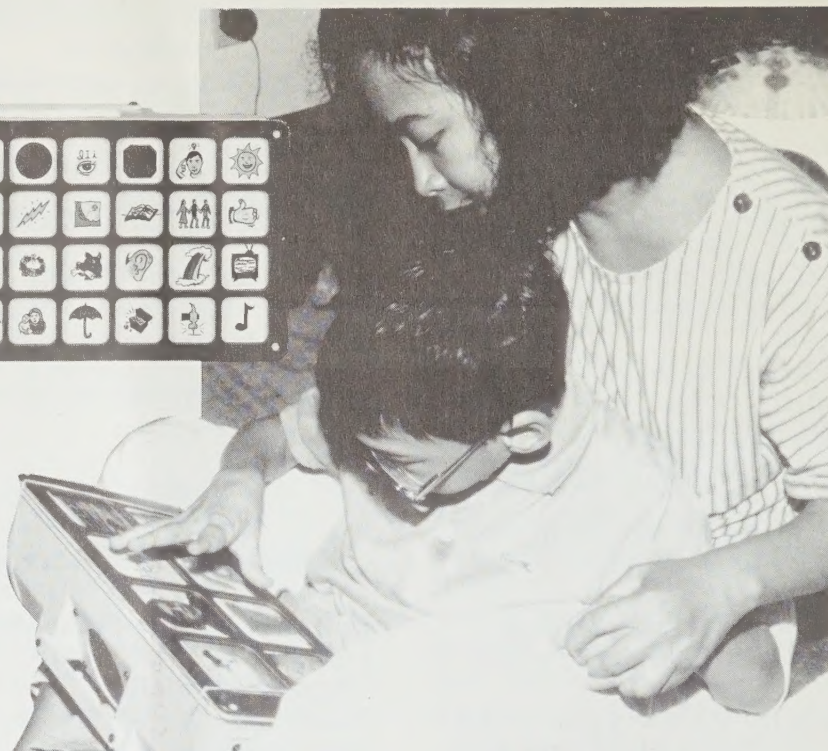
1) Using a collaborative consultative model, to develop and implement services to improve the quality of education for nonspeaking children and young adults.

2) To educate, inform and increase the awareness of the community about the needs and abilities of nonspeaking children and young adults.

3) To contribute to and participate in the growing field of augmentative and alternative communication.

4) While supporting a number of communication systems, to recognize the system of Blissymbolics as a valuable means to advance augmentative and alternative communication.

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